

the time. Whereas 43% and 71% of husbands stated they would be willing to give up >6 mos of a 7-year survival to avoid a 40% and 80% risk of impotence, respectively, only 14% of wives would be willing for their husbands to give up to 6 mos of life to preserve potency at any level of risk. For incontinence 14% and 29% of husbands vs. 0 and 14% of wives stated they would be willing to give up, or have their husband give up, >6 mos of a 7-year survival to avoid a 10% and 30% risk of incontinence, respectively. When surgery, radiotherapy and watchful waiting (WW) were presented with the same life expectancy but a 99% risk of impotence with the first two options and potency with the latter, 57% of husbands vs 14% of wives chose WW. When the same treatment options were presented with the same life expectancy but a 99% risk of incontinence with the first 2 options and urinary continence with the latter, 71% of husbands vs 14% of wives chose WW. **CONCLUSION:** Wives had a higher utility than husbands for any treatment option vs. WW, that prolongs the husbands life regardless of level of risk of quality of life decrements. Wives' preferences were more congruent with observed (vs. stated) preferences of the husbands.

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**DEVELOPING A MEASUREMENT STRATEGY FOR PATIENT-REPORTED OUTCOMES: FINDINGS FROM THE NCI'S CANCER OUTCOMES MEASUREMENT WORKING GROUP**

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**OBJECTIVES:** The National Cancer Institute established the Cancer Outcomes Measurement Working Group (COMWG) in 2001 to assess the state of the science of cancer outcomes assessment and to identify areas requiring further research to move the field forward. During this session, we will focus on COMWG findings related to designing a patient-reported outcomes (PRO) measurement strategy. **METHODS:** As part of the COMWG's mission, literature reviews of PRO studies in breast, colorectal, prostate, and lung cancer were conducted and the performance of different measurement strategies (generic, general cancer, cancer site-specific, unidimensional instruments) were compared. Also, the role of modern psychometric techniques was explored. **RESULTS:** In designing a measurement strategy, there is often a trade-off between comparability and sensitivity. The ability to compare and contrast findings across studies is enhanced when more generic and widely-used instruments are employed. However, using a specific instrument targeted to the particular dimensions hypothesized to differ between groups can enhance sensitivity. Targeted unidimensional measures were more effective at identifying differences between groups than generic and general cancer measures. The importance of using targeted measures that will be effective in identifying differences between groups was felt by many COMWG investigators to outweigh the

potential usefulness of adopting a core set of measures to promote comparability, although, given sufficient resources, including both kinds of measures could be useful. In the future, the use of modern psychometric techniques, including item response theory, may render moot the debate between sensitivity and comparability. As item banks and computer-adaptive assessments are developed, specific targeting of items can occur and, because all items are calibrated using a common metric, comparability can be promoted. **CONCLUSIONS:** In designing a measurement strategy, the relative performance of the different approaches requires consideration. Modern psychometric techniques might contribute to designing a measurement strategy that provides both sensitivity and comparability.

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**HEALTH-RELATED QUALITY OF LIFE BURDEN OF HEAD AND NECK CANCER**

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**OBJECTIVE:** To examine the health-related quality of life (HRQL) burden of head and neck cancer (HNC) and HRQL issues related to its treatment. **METHODS:** A computerized, systematic literature search was conducted of the English-language literature published between 1990 and 2002. Augmenting the electronic identification of articles, manual searches were conducted of the retrieved article bibliographies and appropriate conference proceedings (1999-2002). Type of study and analyses conducted, specific domains affected, factors associated with short- and long-term HRQL, and impact of treatment modality were examined. **RESULTS:** Of 851 abstracts screened, 97 articles met selection criteria and were reviewed in detail. Forty-six were prospective, longitudinal studies; 51 were post-treatment studies with no baseline data. Less than one-fifth of the studies included multivariate analysis. Before treatment, HNC patients have poorer HRQL than age-matched controls in emotional, physical, and social well-being. Impacts are greater among younger age groups. Treatment especially affects emotional, physical, and social well-being, pain, and eating ability. Important predictors of HRQL include speech and eating ability. Radiotherapy, chemotherapy and surgery have acute, domain-specific impacts on patient HRQL that are distinct from long-term impacts. Emotional well-being remains unchanged or improves with time, while eating ability worsens in the long-term. Physical well-being worsens in the short-term with radiotherapy/chemotherapy and in the long-term with surgery. **CONCLUSIONS:** HNC and its treatment substantially impact the HRQL of patients. Patients typically experience decreased HRQL during or shortly after treatment, but then improved HRQL in the longer term. Future studies should include multivariate analyses to control for